



217 South Street
Waltham, MA 02453
781-891-6270, ext. 102

www.afamaction.org office@afamaction.org

Electronic Newsletter September 2017

Message from the Chairman:

Autumn is always a busy time for everyone. The so-called “lazy days of summer” (which may not be lazy for everyone) are past and many people are caught up in a whirlwind of activities and schedules they haven’t had to deal with for several months.

At AFAM, we are also busy moving ahead with ongoing efforts at the State House to assure that important legislation moves forward. This work wasn’t neglected during the summer, of course, as AFAM and its partners offered testimony on a number of bills that directly affect the wellbeing of our families. YOU can help by becoming more involved in our advocacy. There is nothing more powerful than the voices of self-advocates, parents, and siblings in bringing the needs of the autism community to the attention of legislators. You can also contribute to our work by volunteering to serve on one of AFAM’s committee: Government Affairs, Children’s Services, Employment, Adult Services, and Development. If you are interested, email Judy Zacek, AFAM Administrator (AFAMoffice@yahoo.com) or call her (781-891-6270, ext. 102); she will put you in touch with the committee chairperson.

AFAM is moving ahead in another way: stepping up our social media activities so that more people know about the key role we play in advocacy. If you haven’t already done so, please “like” us on our Facebook page and follow us on Twitter. And be sure to tell your friends about AFAM. There is strength in numbers – you can help expand awareness of the work we do.

Michael J. Borr, AFAM Chairman

Would you – or someone you know – like to work for AFAM? AFAM is seeking to contract for a part-time Social Media Manager (SMM) to develop AFAM’s social media presence and manage all AFAM social media accounts. The holder of this position shall be considered an independent contractor and shall be paid on an hourly basis at a rate to be negotiated. The amount of work required will be on an as-needed basis and will vary; there is no minimum number of hours per week, month or year guaranteed. However, it is not expected that the time required fulfilling the job responsibilities in the busiest of weeks will exceed six hours.

The SMM will (a) implement a social media strategy using a combination of tools such as Facebook, Twitter, Instagram and YouTube, as well as other social media accounts and (b) coordinate with AFAM's webmaster to assure consistency between the website and other social media..

Qualifications:

The SMM should:

- be expert in developing social media strategies to build audience relationship and optimize web content;
- possess demonstrated knowledge of end-user computer technologies, including website and social media programs and applications and social media analytic tools such as Google Analytics;
- possess excellent communications skills, including strong and proven writing ability;
- possess the ability to work collaboratively to get the work done in a timely and expeditious manner;
- demonstrate knowledge of autism and advocacy; and
- demonstrate solid understanding of AFAM's mission and voice.

Please send letter of interest and resume to Advocates for Autism of Massachusetts c/o Judy Zacek, 217 South Street, Waltham, MA 02453 or email letter of interest and resume to AFAMoffice@yahoo.com.

Adult Services

Ready to Make an Impact? We Need You! Join AFAM's Adult Service Committee and Step Up to Lead Our Employment Task Force

With the dramatic growth in the numbers of young adults with autism in Massachusetts, we need to up our game and advocate for creative strategies to increase employment opportunities for people with autism. The AFAM Adult Services Committee needs a pro-active, committed advocate to lead its Employment Task Force.

What Does AFAM's Employment Task Force Do?

The AFAM Employment Task Force advocates for an increase in paid employment opportunities for people with autism in Massachusetts. The Task Force explores ways to encourage the adoption of creative public and private strategies to enhance job training, job development and employment opportunities.

The members of AFAM's Employment Task Force are:

Brittany Collins, Doug Flutie, Jr. Foundation for Autism & Flutier Enterprises
Jessica Flannery, sibling
Anke Kriske, parent

Michelle Labadini, parent

Heather Lomartire, BCBA, Vice President of Employment and Day Supports, Charles River Center

Eric Olson, parent

Daphne Romanoff, parent

David Rosenzweig, self-advocate

What's required of the Chair of the Employment Task Force?

The Employment Task Force meets every four to six weeks, at the discretion of its Chair. Its meetings can be held in person at the Arc Mass offices in Waltham or virtually by teleconference (or a combination of both). The Chair is responsible for scheduling Task Force meetings, setting the meeting agenda in consultation with Task Force members, following issues concerning employment of people with autism at the state level, and reporting about the activities of the Task Force to the Chairs of the Adult Services Committee. Occasionally, the Chair may be asked to attend a meeting of the AFAM Executive Committee to discuss Task Force initiatives. Background knowledge about the employment situation for people with autism, state employment supports, and the state legislative and regulatory process would be helpful, but is not required. A passion for advocacy, a willingness to learn, and a pro-active attitude are required!

If you are interested in taking on this opportunity to engage in and shape advocacy for employment for people with autism in Massachusetts, please email the AFAM office at AFAMoffice@yahoo.com.

Children's Services:

The school interpreter bill (H2025 – An Act Relative to the Certification of Interpreters in Educational Settings) will have a hearing before the Joint Committee on Education on **September 5th at 10AM in Gardner Auditorium in the State House**. This legislation directs the Department of Elementary and Secondary Education (DESE) to create standards and competencies for use of interpreters in schools in order to provide limited English proficient (LEP) families with competent interpretation services. School districts are already required to provide interpreter services for LEP families. However, many families across the Commonwealth continue to face significant language access barriers. Currently, many school districts rely on untrained employees or volunteers who are often unqualified as interpreters and unprepared to adequately interpret information. As a result, too many parents are provided inaccurate information, are unable to participate meaningfully in their child's education

It will be very helpful to have community leaders, advocates and parents present at the hearing to testify. In the alternative, letters of support for the bill with relevant experience and parent stories are also helpful to help legislators understand the impact this bill could have. If you have a community group member that needs this information in a language other than English, or wants to write the letter in their native language, or you just have general questions about the bill, please email or call Tere Ramos (tramos@mlri.org) or 617 357-0700 x350. You can also direct questions to Tina Fitanides at MAC tfitanides@massadvocates.org. Please SPREAD THE WORD to all of your coalition members and community members who may be interested in testifying on this bill and/or writing letters of support.

Government Affairs:

Legislative Update: DDS budget challenges, legislative hearings and regulation advocacy work

The FY18 budget landed on the Governor's desk with some cuts to DDS line items from Conference Committee only to have additional vetoes from the Governor affecting services for individuals with autism. Below are the cuts we are facing;

- Cuts to both community residential and state operated homes, approximating 20 million
- Day and employment line item cut by 3 million
- Other DDS lines items totaled hundreds of thousands of dollars in cuts
- Adult Family/Foster Care cuts remain

Overrides have been requested through testimony at the Ways and Means hearing in early July.

On a positive note, AFAM's priority legislation is off to a great start this session.

S 2132, The Accessory Units Housing bill has passed through the housing committee. AFAM has prioritized this legislation for the past two sessions. We are grateful for the support from Senator L'Italien (Bill Sponsor) and for the work of Autism Housing Pathways and The Arc.

S 698/H 634, Inclusive Concurrent Enrollment Initiative has been heard by the Joint Committee on Higher Education. AFAM presented written and oral testimony and the bill was well supported through our partner organizations such as Massachusetts Advocates for Children and The Arc.

Our third piece of priority legislation, H 2276 Criminal Justice and Police Training in Autism, does not yet have a scheduled hearing date. AFAM will be ramping up to prepare for hearing by reaching out for testimony (oral and written).

All three of these bills need our continued advocacy so please be in touch with your legislators, the respective committees or with Maura Sullivan at sullivan@arcmass.org to learn more or to join in on AFAM's efforts.

Upcoming Hearings of interest to the AFAM community include:

September 12th Dental Access Bill,

October 24th Operation House Call and Hospital Training in Autism

Other advocacy efforts this summer have included;

- Testimony was provided in front of EOHHS for regulation changes in CBDS to increase rates, increase staff ratios and drop the lowest reimbursement levels (E and F).
- Testimony was submitted in response to the MassHealth waiver changes including changes affecting premium assistance and narrowing networks to align with the ACO structure.

Please contact sullivan@arcmass.org with any questions.

News and Announcements

You can now make secure online donations to AFAM via PayPal! Just visit our website (www.afamaction.org) and click on the DONATE button.

The Arc of Bristol County's Park Street location has a new Sensory Space, located on the lower level, available to individuals with ASD and related disabilities. The Sensory Space is a quiet and respectable place of retreat for individuals to come and learn ways to stimulate the mind and body as well as relax and self-regulate. This room offers opportunities for self-discovery through meaningful sensory-based activities, including: swings, crash pads, crawl-in cubbies, weighted blankets, tunnels, cause and effect toys, books, and many other items incorporating the senses of touch, sound and sight. The Sensory Space also has a number of visuals and schedules that are available to offer choice and structure for those who are in need of this type of support.

The Sensory Room is available Monday through Friday from 8:30am to 4:30pm. If you would like to use the room, please contact Alison Dulak at (508)226-1445 ext. 3139 to secure a time slot.

The 18th Annual Flutie 5K will take place on Sunday, October 1st at the MetroWest Medical Center's Leonard Morse campus in Natick, MA. Race day registration/number pick-up begins at 9:00 a.m. and the race will begin at 11:20 a.m.. The fee is \$30 for adults (13 and older) and \$20 for children (12 and younger). Register online at www.flutiefoundation.org. The first 800 registered participants will receive a free race shirt. Runners and walkers alike are welcome!

Autism Speaks, New England has scheduled 3 fundraising walks this fall:

September 19th: Northern New England Walk, Manchester, NH

September

23rd: Western New England Walk, Westfield, MA

October 15th:

Greater Boston Walk *on the Boston Common this year!*

HMEA'S Autism Resource Central will hold its **20th Anniversary Gala and Awards Ceremony** on Friday, October 20 from 6:00 to 11:00 p.m. at Cyprian Keyes Golf Club (184 East Temple Street, Boylston). Tickets are \$75 per person. The event, which includes cocktail hour, awards ceremony, dinner, silent auction, and dancing is for ages 21+ only. Cocktail attire is suggested. Reservation deadline is October 6. For further information and reservations, call 508-835-4278 or visit www.autismresourcecentral.org .

The 14th Annual Shared Living & Adult Family Care Conference will take place on Tuesday, September 26 at the Best Western Royal Plaza Hotel in Marlboro. This year's theme is "People, Real Lives, Real Homes." The full day program includes keynote speaker Emily Perl Kingsley, breakfast and lunch, morning and afternoon workshops on a range of topics, exhibits and networking opportunities. For detailed information and to register, visit <http://sharedlivingandafconference.com/>

Autism Speaks wants your input as it develops its next 3-year strategic plan for science.

The link below will take you to a brief survey soliciting your thoughts on the kinds of research you want us to emphasize – as well as any areas you think we should avoid. Your guidance is essential as we reassess how we meet the evolving needs of the autism community as well as build on recent advances in autism research.

We want to include input from all our stakeholders – individuals on the spectrum, families, researchers, clinicians and other autism advocates. We look forward to sharing the survey results – as well as our new strategic plan for science – in the months ahead.

[Take the 2017 Autism Speaks Science Planning Survey here.](#)

SAVE THE DATE! Massachusetts Advocates for Children will hold its **Celebrating Voices Annual Gala** at the Sheraton Boston Hotel on Tuesday, October 24, spotlighting MAC's longstanding advocacy for children and youth with disabilities. Honorees are the Honorable Alice Wolf, former member of the Massachusetts House of Representatives, who is being honored as Legislative and Policy Champion for Children, and Oswald "Oz" Mondejar, Senior Vice President, Partners Continuing Care, who is being honored as Visionary Leader in Workforce Inclusion. For further information, including sponsorship of this event, call 617-357-8431, ext. 3242.

The Friends of Lurie (the Lurie Center for Autism) present **Coffee Convo**, a presentation and discussion series held on the 3rd Wednesday of the month from 6:30 to 7:30 p.m.

Here are the programs that have been scheduled for September, October and November:

September 27, 2017: "Effective Special Needs Parenting: The Necessity of Self-Care," presented by Sylvia Fogel, MD

October 18, 2017: "Autism and Gender Identity, presented by Alyssa Milot, PhD and Andrew Harris, MEd

November 15, 2017: "Helping Your Child Manage Anxiety," presented by Scott McLeod, PhD

Registration is required: Email: LurieCenter@partners.org or call 781-860-1700

For more info about the Lurie Center, visit www.luriecenter.org

The Massachusetts General Hospital Lurie Center is offering a series of small-group informational workshops for parents, caregivers and families about **Understanding the Guardianship Process in Massachusetts**. All sessions will take place at the MGH Lurie Center (1 Maguire Road, Lexington). Please Note: These workshops are provided by a parent/professional, are **not** intended to provide legal assistance or advice, rather they are informational only. Referrals to legal experts are provided as needed.

The first series, **Guardianship 101: Learn the Basics of the Guardianship Process**, provides an overview of what guardianship is and how it is determined in Massachusetts; the types of guardianships (including limited, Rogers); how to decide if your child needs a guardian and alternatives to consider; a review of how to begin the process and what the Massachusetts probate court requires; the steps you need to follow and a suggested timeline to prepare for your child turning age 18. Guardianship 101 is offered on the first and third Friday of most months, from Noon to 1:00 p.m. The fee: is \$20 per person/family. Registration is required: phone 781-860-1700.

The second series, **Guardianship 102: Learn the Step-by-Step Process for court required Paperwork**, offers a more hand-on group tutorial and will include: where you are in the process and moving forward; a review of relevant checklists for each attendee; guidance with probate court processes and referral to legal resources as needed; guidance on filling out required documentation (petition, bond, citation/giving notice, care plan); and a question and answer session. Guardianship 102 is offered on the second and fourth Thursday of most months from 11:00 a.m. to 12:30 p.m. The fee is \$50 for individual/family for regularly scheduled group time; \$100 for individual appointments. You must specify at the time you call.. Registration is required: phone 781-860-1700.

For additional announcements, please visit the websites of our Founding Organizations

Autism Support Center
6 Southside Road
Danvers, MA 01923
978-777-9135

www.ne-arcautismsupportcenter.org/

HMEA's Autism Resource Central
71 Sterling Street
West Boylston, MA 01583
508-835-4278
Sloring@HMEA.org

www.autismresourcecentral.org

Autism Connections
116 Pleasant Street, Suite 366
Easthampton, MA 01027
413-529-2428
karen.serra@pathlightgroup.org

www.autismconnectionsma.org

Family Autism Center
789 Clapboardtree Street
Westwood, MA 02090
bclark@arcsouthnorfolk.org
781-762-4001

www.arcsouthnorfolk.org/family-autism-center.html

TILL's Autism Support Center
20 Eastbrook Road, Suite 201
Dedham, MA 02026
781-302-4600
Lisa.Connor@tillinc.org

www.tillinc.autism_support.html

Autism Alliance of MetroWest
1881 Worcester Road
Framingham, MA 01701
508-652-9900
ADaigle@advocates.org
PMcKillop@advocates.org

www.autismalliance.org

Doug Flutie, Jr. Foundation
P. O. Box 767
Framingham, MA 01701
508-270-8855

info@flutiefoundation.org

www.flutiefoundation.org

The Arc of Massachusetts
P. O. Box 541603
Waltham, MA 02454
781-891-6270, ext. 102
arcmass@arcmass.org

www.thearcofmass.org

Massachusetts Advocates for Children
25 Kingston Street. 2nd Floor
Boston, MA 02111
617-357-8431
Jlandau@massadvocates.org

www.massadvocates.org

Autism Speaks, Inc. - New England Chapter
85 Devonshire Street, 9th Floor
Boston, MA 02109
617-726-1515

www.autismspeaks.org

Charles River Center
59 E. Militia Heights Road
Needham, MA 02492
781-872-1000
ekilicarlan@charlesrivercenter.org

www.charlesrivercenter.org

The Arc of Bristol County
141 Park Street
Attleboro, MA
508-226-1445
mandrade@arcnbc.org

www.arc.nbc.org

Visit our website: www.afamaction.org

**Before you delete this Newsletter,
forward it to family and friends!**